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### Outcomes, experiences and palliative care in major stroke

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**Is palliative care appropriate for all people with major stroke? A multi-centre, mixed-method, longitudinal study of outcomes and experiences**

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## **Abstract**

### **Background**

Case fatality after total anterior circulation stroke (TACS) is high. Our objective was to describe the experiences and needs of patients and carers, and to explore whether, and how, palliative care should be integrated into stroke care.

### **Methods**

Mixed-methods. We recruited a purposive sample of people with TACS from three stroke services, and conducted serial, qualitative interviews with them and their informal and professional carers at six weeks, six months and one year. Interviews were transcribed for thematic and narrative analysis. The Palliative Care Outcome Scale, EuroQol-5D-5L, and Caregiver Strain Index were completed after interviews. A data linkage study of all TACS patients admitted to these services over six months recorded case fatality, place of death and readmissions.

### **Results**

Data linkage (n=219) showed that 57% of TACS patients died within six months. The questionnaires recorded immediate and persistent emotional distress and poor quality of life. We conducted 99 interviews with 34 patients and their informal and professional carers. Patients and carers faced death or a life not worth living. Those who survived felt grief for a former life. Professionals focussed on physical rehabilitation rather than preparation for death or limited recovery. Future planning was challenging. 'Palliative care' had connotations of treatment withdrawal and imminent death.

### **Interpretation**

Major stroke brings likelihood of death but little preparation. Realistic planning with patients and informal carers should be offered, raising the possibility of death or survival with disability. Practising the principles of palliative care is needed, but the term "palliative care" is unhelpful.

## Introduction

Stroke is the second-leading global cause of death, accounting for 11% of deaths worldwide.(1, 2) Five year survival is similar to all cancers combined and heart failure.(3) Prognosis is particularly poor for patients with total anterior circulation syndrome (TACS) strokes; i.e. the ‘full house’ of unilateral motor or sensory loss with cortical symptoms (e.g. aphasia or inattention) and homonymous hemianopia.(4) A physical trajectory for patients with severe stroke has been proposed of sudden decline in functional status at stroke onset, and ending in death or survival with long term disability.(5)

Palliative care seeks to support people to live well with deteriorating health until they die, and improves outcomes when introduced early alongside disease-modifying treatment.(6, 7) The World Health Organisation recommends that holistic care for people with *any* life-threatening illness should include the key principles of palliative care.(8) Patients with severe stroke and their informal carers\* stand to benefit when their physical, psychological, emotional, spiritual and practical needs are anticipated and addressed.(9-11) Cohort studies and qualitative research in patients with major stroke have identified difficulties with symptom management, communication, family support and proxy decision-making among patients dying with acute stroke.(12-15) However, there is insufficient detail about the immediate and long-term psychological, emotional and spiritual needs of stroke survivors and their informal carers to understand whether, and how, palliative care should be integrated into stroke care. A mixed-methods approach was considered the most appropriate method to explore these dynamic complex issues.(16)

Our objective was to understand patients, informal and professional carers’ experiences, concerns and priorities in the 12 months after TACS stroke and to identify the potential role of palliative care within stroke care, both in hospital and the community.

\*The term “informal carer” is used to include family or unpaid carers

## **Methods**

### *Design*

We used a mixed-method approach using a) individual in-depth interviews with patients, informal carers and health/social care professionals, or joint interviews with patient and carer, b) questionnaires if patients and carers were able to complete them, c) data linkage study of all patients with TACS admitted to the three participating stroke units to explore patterns of death. We specifically utilised serial qualitative multi-perspective interviews as this is a robust method for understanding evolving and complex processes.<sup>(17)</sup> We utilised questionnaires to allow a numeric comparison using standardised measures across the interviewees, and to observe how they might perform serially in a future trial.

### **Data generation**

#### *Qualitative aspects*

The qualitative study included TACS patients with a modified Rankin score of 4 or 5. In order to capture a range of experiences, we aimed to recruit a minimum of 10 patients in each of the dichotomous groups of age (70 or over, or less than 70), gender, artificial or oral feeding, right and left hemisphere stroke, significant comorbidity or not, and at least 5 people who were expected to go home. In total, we aimed to recruit around 30 patients because this was expected to achieve saturation, based on our previous experience of serial qualitative interviews in other end-of-life patient groups.<sup>(17)</sup>

Patients admitted to three stroke units in Scotland, and/or their legally-recognised representative or next of kin, were identified and approached by a clinician or a Scottish Stroke Research Network nurse working in a stroke unit in three Scottish Health Boards between June 2014 and January 2015. We used a recruitment grid to ensure we recruited the required diversity of participants. Consent was obtained from those patients with capacity (using aphasia ‘friendly’ materials if needed). Proxy consent was obtained for patients with incapacity. Participants were then contacted by a researcher. See box 1 for special considerations we adopted for people deemed not to have capacity.

Two experienced female qualitative researchers (nurse researcher and senior social scientist) undertook the interviews with stroke survivors and/or their informal carer/relative at six weeks, six months and one year.(18) At each time point, participants nominated a key health or social care professional for interview. Patient and relative interviews took place in the hospital ward or in their homes/residential care. Professionals were interviewed at their workplace or by telephone. The interviews took a narrative approach using topic guides which included, for instance with professionals how they perceived “palliative care”. Patients and carers were not asked directly but if they raised the topic of end-of-life care/death/dying this was explored using their terms, and they were asked if they had heard of palliative care, and what they understood it to mean. Interviews lasted 20 to 90 minutes, were digitally recorded and fully transcribed with field notes.(19)

Two lay advisory groups – one from a support group for patients with stroke and their informal carers, and another from a group specifically for people with speech loss regularly discussed emerging findings. An end-of-study focus group of informal carers, stroke clinicians, general practitioners, geriatricians, palliative care specialists, allied health professionals, care home managers and policy-makers, considered emerging recommendations.

### *Questionnaires*

After each interview we mailed patients the EuroQol 5D-5L (quality of life) and the Patient Outcome Score (multi-dimensional needs) and carers the Carer Strain Index (caregiver wellbeing).(20-22).

### *Data linkage*

We obtained Scottish Stroke Care Audit (SSCA) data for all patients with TACS admitted to the three stroke units during the six months of recruitment to the qualitative study. We linked these data with hospital and National Register for Scotland data for the year after the index stroke, to describe temporal patterns of death.

### **Data Analysis**

The qualitative analysis was iterative and ongoing alongside further data generation. It was guided by the research questions, key theoretical concepts in the literature, and assimilated themes arising from the data. We performed thematic and narrative analysis and used a constructivist and interpretivist framework.(19, 23) Principles of grounded theory were used in the sense that data analysis was iterative and guided by emerging themes as well as by the research questions.(24) We were thus open to new ideas or themes as well as being able to situate our findings within the existing theoretical landscape. The interviews with individual patients, carers and professionals were initially coded separately. Then, each set of individual patient's and/or carer's transcripts were analysed over time to identify dynamic changes, generating 29 individual case studies. Next, patient transcripts were analysed together to gather patients' perceptions, informal carer transcripts analysed to examine the carers' perspectives, and health care professional transcripts analysed to gain their perspectives. Finally, all the transcripts (patients', carers' and professionals') from each of the three time points were analysed together to look at issues specific to each point. The insights were integrated with the assistance of NVivo 10 to show common themes and divergent perspectives.(25) We then traced themes across the three data sets to give an in-depth multi-perspective picture of experiences and outcomes.(26)

We triangulated between methods and between the views of the various participant groups to enrich our understanding of the data mainly employing the mixed-methods matrix approach which integrates both qualitative and quantitative data for each participant at the analysis stage of the study.(26) Deviant cases, or accounts of experiences that differed from those commonly reported, were scrutinised to refine our comprehension of emerging narratives.(27) Early in the study, the interviewers (MK, EC) reviewed each other's initial interview transcripts to ensure similarity of interviewing approach. MK coded all the transcripts and met frequently with a principal investigator (SAM) to discuss the emerging findings. The evolving analysis was peer-reviewed by the investigator group at quarterly meetings. We established an audit trail using field notes, recruitment logs, records of meetings and analytical discussions, and made regular reports to the study funder. We used multiple data collection sites to enhance the transferability of our findings and undertook data



linkage to enable a description of the wider study context, in terms of outcomes for a cohort of TACS patients.

## **Results**

Two hundred and nineteen patients with TACS (185 ischaemic stroke (85%); 33 haemorrhagic stroke (15%)) were admitted to the three participating stroke units during the study recruitment period. Six month case fatality was 57% (125 deaths). One year case fatality was 60% (132 deaths); of these deaths 88 (67%) occurred during the first four weeks.

We recruited 34 patients to the qualitative study (Table 1) and performed 99 qualitative interviews (Table 2) over the first year after stroke. Between half and two-thirds of questionnaires were returned; these showed anxiety of family or friends, low self-worth, lack of information, difficulty sharing feelings, and emotional distress (Table 3). See Box 2 for specific details according to specific data sources including data linkage. We present the integrated findings from the three methods.

### **Experiences and key concerns of patients, informal carers and professionals**

A typical trajectory of physical decline with people with TACS is illustrated in Figure 1 based on the findings generated from our mixed-methods. This extends and enriches Creutzfeldt's proposal for a "fourth trajectory"(5). It visualises how the typical physical functioning of patients who have survived the stroke tended to progress during the following 12 months. The percentages of patients surviving at one, two, six and 12 months are also shown. Key quotations are in Box 3.

#### ***Phase 1: Sudden illness and acute hospital admission***

The sudden unexpected event of major stroke came as a major life crisis. Its life-threatening but unpredictable course posed huge challenges for patients, informal carers and professionals. Although the possibility of dying was clear to all involved, it was rarely voiced. Family members were unsure whether they were 'doing the right

thing' for patients (Q1). Participants faced complex care-planning decisions about resuscitation and feeding interventions (Q2).

Communication with informal carers and amongst staff was often challenging, as circumstances could change rapidly and many patients had lost capacity. Patients and carers expressed "dual narratives"; i.e. the narrative of a good recovery competing with a more realistic account of disability or death. Everyone had thoughts about death, but most patients felt unable to raise these with professionals. When the stroke first occurred, professionals aimed at life-saving treatment unless the patient was clearly dying, so professionals and patients expressed hope for a good recovery, even if death had been mentioned as a possible outcome. This sometimes confused carers (Q3). Staff confessed to be over-optimistic in order to motivate people and encourage participation in physical rehabilitation (Q4).

Many patients and informal carers would have welcomed more support in making decisions and in planning for the future from day one. The focus was on active rehabilitation, recovery, motivation and hope, with much less discussion and preparation for limited recovery. Many professionals gave time and listened and communicated well, but future planning was less evident (Q5&6).

### ***Phase 2: Rehabilitation and transition to the community***

Emotional needs and ability to adapt to a radically altered life varied. Some said it was difficult to see life as "*a life worth living*" (Q7).

As in the earlier phase, maintaining a sense of dignity and personhood was central. In rehabilitation wards, where people felt trapped, as they could not be discharged home until their physical abilities improved. Some carers and patients began to suggest that it would have been better if the patient had died, rather than living with severe disability. The sort of life deemed "unacceptable" was subjective; some accepted their disability; others with a better physical recovery felt discontented and grieved for their former life (Q8&9). These carers felt that there was less forward planning than in other illnesses (Q10).

Most patients wished to return home initially, but later realised this was complex, being compounded by pressure on hospital and care home beds (Q11).

### ***Phase 3: living with major stroke in the community***

Many people, especially those with aphasia and cognitive impairments, found difficulties in accessing services and equipment. Some felt abandoned and experienced loss of hope and meaning. This was exacerbated once professionals assessed patients as having reached their “plateau”, when many services were withdrawn (Q12). Those who returned to living at home had to adjust to a very different way of life and a home disrupted by hoists, commodes, and boxes of medication (Q13).

Most patients and their informal carers came to appreciate the advantages a good care home offered when they could not manage at home. Although one family member still wanted to take their parent home (Q14). For informal carers a nearby care home with friendly staff that inspired trust was important. Many care homes provided equipment and care that was difficult to achieve at home (Q15). Many informal carers felt that future care planning for both recovery and deterioration would have been helpful (Q16).

A few people died in care homes, where care home staff generally managed discussions and decisions sensitively. However one participant was shocked when the care home GP approached her as she visited her relative and initiated an end of life conversation without any warning (Q17).

### **Is ‘palliative care’ appropriate for people with major stroke?**

Some staff viewed the term ‘palliative care’ as something negative, and applicable only to someone who was clearly dying (Q18 & 19).

Professionals actively sought to offer holistic care to patients and carers, but also struggled with the words ‘palliative care’. Barriers included prognostic uncertainty, although this doctor understood that this may remain, even after introducing a palliative approach (Q20). Professionals spoke about the need for everyone involved in patient care to have the time and ability to communicate effectively, with referrals being made to specialist palliative care only when required (Q21).

One bereaved relative suggested following a routine approach to document preferences (Q22). Using the word insensitively with patients could upset them (Q23). One hospital doctor suggested that the word may best be avoided (Q24).

## **Discussion**

**Summary:** Patients and their informal carers faced sudden complex decisions, anxiety, distressing symptoms and the likelihood of death. Professionals focused on active physical rehabilitation, recovery, motivation and hope, and took less account of psychological, social and existential needs. Future care planning was difficult because of uncertain prognosis, variable and changing understandings, expectations and coping strategies.(28) Transition home or to a care home brought feelings of abandonment. Some experienced a lack of hope and meaning, and grief for a former life. The term 'palliative care' was equated with 'last-days-of-life' care by health care professionals, patients and family.

### **Comparison with other studies**

Previous studies have identified high case fatality after severe stroke, multiple long-term physical problems, significant emotional distress, prognostic uncertainty, and a sense of abandonment after hospital discharge.(10, 29, 30) Our study confirms and adds richness to these findings, and adds several new insights. Firstly, staff focused on active physical rehabilitation, recovery, motivation and hope, whilst patients and carers felt that they needed more preparation, for, and discussion of, the possibility of death and living with severe disability. The questionnaires documented poor quality of life and multi-dimensional needs, and highlighted anxiety and carer distress throughout. Patients described a degree of suffering consistent with considerable unmet palliative care needs. Secondly, for those patients who survived, there was grief amongst both patients and family for the loss of their previous life, identity and roles; this could be considered as an evolving bereavement process, with some patients and family wondering if death would have been preferable to survival with disability. This evolving process has also been reported in severe head injury and dementia.(31, 32)

Thirdly, patients and professionals found the term 'palliative care' difficult to use, as it was equated with 'end-of-life' care and withdrawal of treatment. This is still true even in people with cancer.(33) This contrasts with how it was defined and recently affirmed by the WHO as active treatment to prevent distress starting from diagnosis of a life-threatening illness (see Box 4).

### **Strengths and limitations**

Strengths included the mixed-methods design, with serial multi-perspective interviews dynamically integrating data from patients, informal and professional carers and rigorous analysis with service user involvement to aid interpretation. For instance the service user involvement explicated the challenges of accessing support when people have aphasia, and the experience of discharge back to the community after a long admission. To promote credibility and generalisability and transferability of the data we sought to find exceptions, then used triangulation (multiple methods of data collection, data sources, researchers or theories), to obtain a high level of concordance in category development. We adopted a relatively large longitudinal multi-site interview study to enable prolonged engagement in the field and used a varied sample to ensure that a range of perspectives were explored.

Limitations included that we recruited patients from Scotland only, some patients participated in only one interview because of loss to follow-up or death (though we performed several bereavement interviews with informal carers), and the sample was all white British. No formal training in palliative care had occurred in any of the stroke units, although some online learning was available: this is likely to be the case in most facilities internationally.

### **Conclusion and future directions**

A realistic model of care would be to prepare for survival, decline or death, balancing "hoping for the best" with "preparing for the worst."(5) This palliative approach more often occurs for patients with progressive cancer and increasingly for people with non-malignant conditions such as heart, lung and renal failure and frailty.(34) Shared decision-making and individualised care is crucial.(30, 35-37) Staff need to be supported and trained in talking openly and honestly about the possibility of death or survival with severe disability, particularly in the acute setting

where the majority of deaths occur. Models of bereavement support might help professionals to facilitate both the more traditional restoration-orientated approaches to rehabilitation and loss-orientated rehabilitation that allows people to express and work through devastating life changes.(38) The principles of palliative care should be embedded within stroke services, but the term ‘palliative care’ should currently be avoided or reframed because of the implications of abandonment rather than a positive approach to care.(33, 39) Some specific recommendations are offered in Box 5.

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**Contributorship:** GM, MK, EC, MB, CM, DS & SAM conceived the study and contributed to its design. GM and MK prepared the application for ethics approval and the patient information leaflets. MK led the study and undertook data collection and initial analysis with EC. All authors were involved in the interpretation of the data and reviewing the early and final drafts.

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**Data Sharing:** Further data may be available from GM.

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